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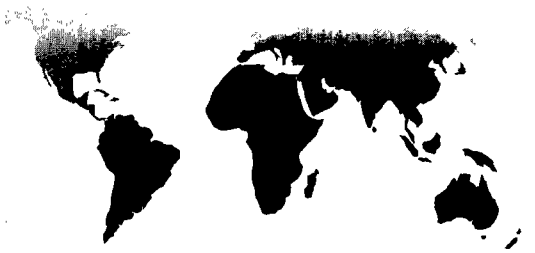
Healthy Ageing – Adults with Intellectual Disabilities

Women's Health and Related Issues



International Association for the Scientific Study of Intellectual Disabilities

WHO Global Movement for Active Ageing

Department of Mental Health and Substance Dependence
World Health Organization

Healthy Ageing - Adults with Intellectual Disabilities

Women's Health and Related Issues

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1.0 Background

1.1 This report is concerned with issues which are important for the health of women with intellectual and developmental disabilities as they grow older and age. The specific focus on women's health is in no manner meant to be dismissive or designed to minimize concerns related to men's health issues. However, it is the position of the SIRG on ageing that women's health issues have not received appropriate and sufficient attention, that women as they age are subject to sex-related conditions and changes, and that in many instances the interests and needs of ageing women and women with disabilities are overlooked or neglected. Thus, this report is designed to explore factors related to well-being and quality of life for women, to examine and define sex-linked differences in their life experiences and opportunities and to define their distinctive vulnerabilities -including research on health status and access to health care.

2.0 Women's Health - a Global Perspective

2.1 The human rights of women and girl children are an integral part of universal human rights, according to the UN Vienna Declaration. Ensuring their full and equal participation in all aspects of life in society, without discrimination of any kind, is a priority objective for the international community. The United Nations Commission on the Status of Women promotes the well-being and education of the girl child as a priority for global action in its policy documents (1998). Further, the UN Standard Rules identify the availability of suitable medical and health care as an essential perquisite if people with disabilities are to enjoy equal opportunities in the societies where they live (UN 1994).

2.2 Regional policies have adopted human rights as the basis for all actions related to the lives of persons with disabilities. Social policy within the European Union of 15 countries has replaced traditional care models of disability with a rights-based model. Human rights are expressed as equal opportunities for all citizens, particularly those with disabilities, to take part fully in all aspects of everyday life in their own societies (CEC 1996). A respect for human diversity should thus inform all aspects of social planning.

2.3. The WHO - Global Strategy on the promotion of women's health falls within this rights-based framework: The right of all women to the best attainable standard of health - as well as their right of access to adequate health services - has been a primary consideration of the World Health Organization (United Nations 1997b:10)

2.4 There have been dramatic increases in life expectancy during the 2Oth century, due chiefly to tremendous advances in medicine, public health, science and technology. However, the quality of human life is as important as its length - perhaps even more important. Today, individuals are concerned about their health expectancy - that is, the years they can expect to live in good health (WHO 1997). Inequalities exist, based on sex, region and social status. The poorest, least educated people live shorter lives with greater ill-health. Globally, while life expectancy increases, disability-free life expectancy seem to be stabilizing.

2.5 Priority areas for international action in health should be: a comprehensive chronic disease control package incorporating prevention, diagnosis; treatment and rehabilitation and improved training of health professionals; fuller application of existing cost-effective methods of disease detection and management, a global campaign to encourage healthy lifestyles; research into new drugs and vaccines and the genetic determinants of chronic diseases; and alleviation of pain, reduction of suffering and provision of palliative care for those who cannot be cured (WHO 1997:136).

3.0 Lifespan Perspective: Ageing and Health

Recently, more attention has been given to the personal and social development of girls and women with developmental disabilities throughout the lifespan. This approach attempts to understand their experiences and their engagement with the tasks considered appropriate in their family and culture at each transitional stage - infancy, childhood, adolescence, early - middle - and late adulthood, and old age. For example, young women in many industrialized societies typically complete formal schooling and/or vocational training, find employment, achieve full citizenship and build personal friendships and intimate relationships. Some may establish homes and start childbearing. Women in late adulthood who have been employed may retire from the active workforce, attend more to personal interests - depending on their income and talents - and perhaps devote themselves to grandchildren or other family concerns. And as they age, women and men increasingly value good health and the independence and mobility it brings.

3.1 Populations are ageing. The number of people aged 65 years and above account for 7% of the world's population: two-thirds (65%) of those aged 80 and above are female. Global strategies must take gender differences into account. A major challenge will be to develop innovative ways of tackling the special health and welfare problems of elderly women (WHO 1997:11). From the perspective of the WHO, healthy ageing is a global priority. The need to focus on promoting health and minimizing dependency of all older people is a principle of action common both to more developed countries - where 12.6% of the population is elderly - and to developing countries - where only 4.6% is elderly (WHO 1995:2).

3.2 Gender and health. The differential impact of gender on health is not static; rather it reveals itself as the individual grows and develops throughout his or her lifespan. Many risks to health are age-related: Men die earlier, while women experience greater burdens of morbidity and disability. Women constitute the majority of both the carers and the older users in the health sector. Supporting the female carers is a key health policy challenge (WHO 1995:6.1.5).

3.3 UN emphasis. The special situation of women is highlighted in current programs for older persons within development planning. 1999 was the International Year of Older Persons with the theme, "Towards a Society for All Ages." A society for all ages recognizes the rights and responsibilities of all age groups and makes it possible for older persons to live healthy, productive, economically secure lives (UN 1997a: SG/SM/6339 OBV/11).

3.4 Gender is recognized as a determinant of health. A gender approach to health includes an analysis of how different social roles, decision-making power and access to resources affect health status and access to health care. The special needs of women and current inequalities in delivery of health care are apparent. The WHO has targeted increasing its efforts towards: (1) advocacy for women's health and gender-sensitive approaches to health care delivery and development of practical tools to achieve this; promotion of women's health and prevention of ill-health; (2) making health systems more responsive to women's needs; (3) policies for improving gender equality; and (4) ensuring the participation of women in the design, implementation and monitoring of health policies and programs, in WHO and within countries (WHO 1997:83).

3.5 Health status. Data gathered about the health of women living in developed nations indicate that while these women live on average up to about 80 years, many die prematurely before the age of 65 due to accidents or diseases which could largely be avoided by healthier living or early detection. Special health issues are important to women at different stages of their lives. Eating disorders have serious consequences for younger women, adult women confront

health problems related to HIV and AIDS, and among elderly women, the rising incidence of osteoporosis has become a chief concern for women (CEC 1997:8). In contrast, the health status of adult women in the developing nations is often compromised, resulting in shorter life expectancies, greater rates of illness or disability-related conditions. poorer nutrition, and a greater incidence of problems more related to earlier life stages.

3.6 Policy focus on women's health. Policy-makers may embed the distinctive health needs of women throughout the lifespan in national health strategies. For example, in Ireland, the Department of Health formed a plan for women's health in consultation with many individual women and women's groups throughout the country. The plan, which is in keeping with WHO targets for the health of women, recognizes that some groups of women - those with disabilities, for example -face particular challenges to maintaining good health. Lack of information, lack of access to services and special difficulties related to advice about sexual and reproductive health were identified. The Irish Government document recommends direct consultation with women who have disabilities themselves in order to develop appropriate services (Government of Ireland 1997:63).

4.0 Health, Ageing and Intellectual Disabilities : Cross-CulturalContexts

4.1 Increased longevity and improved services of all kinds have led to an unprecedented growth in the population of persons with intellectual disabilities. It is estimated that as many as sixty million persons in the world may have some level of intellectual disability (WHO *1997).* Older people with intellectual disability have significant physical health needs (Cooper 1998; van Schrojenstein Lantman-de Valk 1998, inter alia). The health of individual men and women with disabilities as they grow older will reflect the social and economic circumstances shaping their daily experiences. Their fortunes may be especially at risk relative to those of their peers or family members. "It is in situations of dire poverty that household members are subjected to neglect, and people with disabilities are particularly vulnerable (Whyte and lngstad 1998: 43).

4.2 Access to health care. Informants from developing, rural or remote regions report that greater access to health care, information, proper treatment protocols, and the like, would all greatly enhance longevity. Many individuals with more severe disabilities do not survive the early childhood years. There may be no surgeons, or no facilities for neonatal care, and poor health outcomes for the elderly. In the Pacific region, for example, diseases such as measles, and dengue fever may be lethal. Given generally poor access to health resources, the population of people with intellectual and developmental disabilities is more likely to be stricken and affected by threats from disease. Cultural differences also influence health care across the lifespan. Local healers and natural medicines may be a mainstay for a community. Further, cultures vary in their understanding of, and attitudes toward, elders, as well as toward women. Such attitudes may influence the availability and accessibility of health care for older women.

4.3 Socioeconomic contexts. Thus, healthy ageing does not arise and maintain itself in a vacuum. Social, political and economic environments interact with the daily lives and experiences of individuals in a given society. Efforts to promote their health and well being reflect this complex interaction. The quality of daily life experienced by individuals both reflects and contributes to the quality of the society in which they live. Providing political environments which foster healthy social relationships, trust, economic security, sustainable development and other factors related to advancing the health and well-being of citizens has been identified as a priority for governments. The quality of social relationships in a society has been documented as part of health outcomes: healthier communities with greater social cohesion produce healthier citizens (Lomas 1997). These and other factors make up a country's social capital, an essential

factor if states are to achieve the priorities for effective health promotion which are listed in the Jakarta Declaration, such as increased investment in health development particularly for needy groups (Cox 1997:3).

5.0 Health and Ageing: Women's Health and Related Issues

5.1 In preparing this report, two key questions were posed in order to inform those charged with implementing global, regional and national health strategies including the needs of women with intellectual disabilities. These questions were (1) What is the current knowledge base about the health of women with intellectual disabilities across the lifespan, especially among older women? (2) What are the practices most effective in promoting good health and satisfaction with services among women with intellectual disabilities?

Three kinds of evidence were used to compile this report. First, information about global and regional trends, demographic patterns and socio-economic indicators were drawn from a range of policy and research documents published by bodies such as the World Health Organization and other groups (Sections 2,3 and 4). Second, research literature in scientific publications was reviewed and three summaries were prepared: these appear in Sections 6.1, 6.2 and 6.3. Third, colleagues in many countries contributed background information about local conditions in their parts of the globe. Qualitative data were yielded by focus groups and other consultative meetings of women with intellectual and developmental disabilities, their families, advocates and professional workers in many countries. The themes which emerged about their experiences of health care and promotion appear in Section 7.

The final section of this report, Section 8, includes recommenda-dations for research, policy and practice.

6.0 Summary Reviews Of Literature

Research summaries related to women's health and ageing are organized across four topic areas and appear in the following three sections. The editors' initials appear in parentheses. The first section (6.1) reviews evidence about cancer and sexual health (H. van S L- de V) and reproductive health (NS). The second (6.2) focuses on promoting health among ageing women with intellectual disabilities (TH), and the third section (6.3) addresses the social, economic and cultural contexts of health (PNW).

6.1 Physical Health And Ageing

6.1.1 Menstruation

6.1.1.1 Among women with intellectual disabilities, the average age at onset of menarche is similar to that of women in the general population. Most appear to have regular menstrual cycles. Recent studies of gonadal function in women with Down syndrome have found distributions of age at menarche and frequencies of women with regular menses that are much closer to those found in the general population than had been presumed from earlier studies (mostly of institutionalized women). Between 65% and 80% of women with Down syndrome have regular menstrual cycles, while 15 to 20% have never menstruated.

6.1.1.2 Methodological problems in studies of hormonal status during menstrual cycles in women with Down syndrome and other intellectual disabilities include small sample sizes, sampling of only a few cycles, and lack of control for the stage of menstrual cycle at which the

blood sample was drawn. Nonetheless, international studies have generally supported the conclusion that most cycles show evidence of ovulation and formation of a *corpus luteum,* suggesting that gonadal endocrine function is within normal ranges in the majority of women with intellectual disability.

6.1.1.3 Many women with intellectual disability are treated with psychotropic medication and/or anti-epileptic drugs (AEDs). Psychotropic medications can interfere with a number of hormonal and metabolic functions. A common finding is hyperprolactinemia in association with neuroleptic drug use. Prolonged elevations in prolactin can lead to declines in follicular (FSH) and luteinizing hormone (LH) release, leading to declines in ovarian function. Reduced gonadal function may lead, in turn, to menstrual disturbances, including amenorrhea or infertility and reduced estrogen release which may increase risk of age-related disorders associated with reduced estrogen levels. Seizures and AEDs may also influence memory and cognition through changes in neuroendocrine function. Elevated levels of sex-hormone binding globulin, FSH and LH have been described and long-term AED therapy has been associated with primary gonadal dysfunction and increased risk of polycystic ovarian syndrome.

6.1.2 Sexual Health

6.1.2.1 Women with intellectual disability have the same sexual needs and rights and responsibilities as do other women. However, care personnel and other carers are not always adequately educated on this issue and may seek to limit opportunities for sexual activity. Older parents may tend to ignore the sexual needs of their children. In many societies, general attitudes toward persons with disabilities and toward women specifically may further serve to deny or trivialize sexual health concerns. Unfortunately, such attitudes may also carry over to women of older age and thus deny access to health services related to gynaecological concerns and functions and may lead to a dearth of health professionals who are willing or trained to address reproductive health issues.

6.1.2.2 People who are sexually active are prone to sexually transmitted disease (STDs). Education on symptoms of STDs and early treatment is necessary to avoid further transmission and development of late-stage complications of the infection. Some STDs are characterized by chronic pelvic pain, vaginal discharge and abdominal pain, but other STDs may be present without clinical manifestations (e.g., 65% of Clamydia infections). However, even when they are symptom-free, infected women may transmit their infections and, untreated, may develop severe complications. Infection with the HIV virus and development of AIDS is of special concern. Currently, in countries from which information is available, it appears that HIV in persons with